

**10 TO LIVE WITH NMOSDS YOU NEED A SUPPORT NETWORK**

The first thing to be aware of is that a diagnosis does not mean letting go of your personal projects, work or studies, friends or family.

It is important to count on the support of expert professionals as well as your network of family and friends to face the challenges and changes brought on by the disease. AINMO, the Italian Neuromyelitis Optica Association provides information, guidance and support to people with NMOSDs and MOGADs, their families and caregivers.

**10**  
THINGS YOU SHOULD KNOW  
ABOUT  
**NEUROMYELITIS  
OPTICA**

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un mondo libero  
da NMOSD  
e MOGAD



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**NEURO  
MYELITIS  
OPTICA**

**10**  
things you  
should know



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## 01 NMOSDs ARE AN AUTOIMMUNE DISEASE OF THE CENTRAL NERVOUS SYSTEM

NMOSDs, or neuromyelitis optica spectrum disorders, belong to a group of chronic and unpredictable conditions. NMOSDs are triggered by a malfunction of the immune system where “faulty” antibodies attack cells of the central nervous system called astrocytes, provoking a chain reaction that damages the myelin sheath wrapped around nerve fibres and neurons thus compromising the transmission of nerve impulses. Signs and symptoms vary depending on which areas of the central nervous system are affected.

## 02 NMOSDs ARE RARE AND AFFECT WOMEN MORE THAN MEN

NMOSDs affect about 1,500-2,000 people in Italy. Women are affected from 4 to 9 times more than men. NMOSDs symptoms generally appear between 35 and 45 years old, but can also affect children and the elderly.

## 03 THE DISEASE IS CAUSED BY A MIX OF FACTORS RANGING FROM GENETICS, THE ENVIRONMENT, HORMONES AND THE IMMUNE SYSTEM

The combination of these factors is still not completely clear. As with many autoimmune diseases, the presence of other autoimmune diseases can make some people more prone to NMOSDs than others.

## 04 THE MOST COMMON SYMPTOMS ARE NEUROMYELITIS OPTICA AND MYELITIS

The most frequent problems affect sight, sensibility and mobility and they can be acute at the outset of the disease or during relapses. Other symptoms include: tiredness, pain, muscle rigidity and spasticity, as well as problems affecting balance, sleep, sexual activity, cognition, the bladder and intestines. These are all symptoms that can interfere with daily life and also impact the quality of life.

## 05 NUMEROUS SYMPTOMS ARE SIMILAR TO THE SYMPTOMS OF MULTIPLE SCLEROSIS

For many years, NMOSDs were considered variants of multiple sclerosis however they belong to a completely different syndrome with particular characteristics which require specific management. Since the discovery of anti-aquaporin-4 antibodies at the start of the 2000s, numerous forms of NMOs have been identified, which is why they are defined as “neuromyelitis optica spectrum disorders”.

## 06 SYMPTOMS ALSO AFFECT PEOPLE'S EMOTIONS

Crucial moments such as diagnosis, a relapse or worsening of the disease are often accompanied by feelings of anger, anxiety, feeling lost, fear of the future, rejection and emotional shut-down. These very intense emotions also affect families, partners and friends: it is important to take care of everyone's psychological well-being.

## 07 THERAPIES EXIST THAT CAN SLOW DOWN THE DISEASE

There are various therapies available today that act on the natural course of the disease: starting these therapies as soon as possible is the best way of reducing the frequency and seriousness of attacks. There are also various types of symptomatic medication and specific rehabilitation strategies which help to manage symptoms on a daily basis.

## 08 EARLY TREATMENT REDUCES THE RISK OF DISABILITY

Relapses can be severe: often the person does not recover completely and is left with neurological damage and disabilities. This is why starting therapy as soon as possible to prevent future attacks of the disease is essential to minimize and reduce long term disability.

## 09 MEDICATION MUST BE ACCOMPANIED BY PHYSICAL ACTIVITY

Physical activity improves mood and self-confidence, posture and balance. Movement exercises muscles and joints thus reducing the risk of falls. Swimming, walking, dance and yoga can be practised by people with sight problems: just ask your doctor. Physiotherapy is crucial to maintain mobility and self-sufficiency, especially after relapses.